ACTA MÉDICA PORTUGUESA
A Revista Científica da Ordem dos Médicos

Neurodevelopmental Psychiatry Consultation: A National Level Analysis

Consulta de Psiquiatria do Neurodesenvolvimento: Uma Análise a Nível Nacional

Joana COSTA ALVES✉[1], Sofia MORAIS[2,3], António FERREIRA DE MACEDO[2,3]
Acta Med Port 2023 Dec;36(12):802-810 ▪ https://doi.org/10.20344/amp.19652

ABSTRACT

Introduction: Neurodevelopmental disorders are characterized by delay or variation in the acquisition of abilities or skills in several domains of development: motor, social, language, and cognitive. These disorders can manifest from childhood to adulthood, and therefore continuity of care is essential throughout these various developmental periods. However, several studies show that there is limited access to adult health care in this clinical domain.

Methods: A cross-sectional observational study was carried out by distributing an anonymous survey among psychiatry physicians, at a national level, in the period between October 6 and December 6, 2020.

Results: Data was collected from 83 psychiatry physicians (43 residents and 40 specialists). At the national level, only 16.9% of psychiatric departments had a subspecialized neurodevelopment clinic. Physicians reported that they observed few patients with neurodevelopment disorders: 72.3% observed one or none per week. When there was a neurodevelopmental disorders clinic in the psychiatry department, 64.3% of physicians reported that this clinic did not include a multidisciplinary team. The transition of these patients from the pediatric/child and adolescent psychiatry department to the psychiatric department occurred through regular intrahospital transfer in 51.8% of cases, but it occurred through a specific protocol or with a transitional medical appointment in only 15.7% of cases. Finally, 88% of psychiatry physicians considered the existence of a neurodevelopmental disorders clinic in adults to be pertinent and reported not having specialized training in the field of neurodevelopment.

Conclusion: This study made it possible to identify some difficulties and barriers regarding adequate access for patients with neurodevelopmental disorders throughout the various developmental stages, from childhood to adulthood: lack of training in this clinical field, need of better communication between departments, lack of specific protocols, shortage of multidisciplinary teams, and asymmetry in the distribution of differentiated care.

Keywords: Attention Deficit Disorder with Hyperactivity; Autism Spectrum Disorder; Mental Health Services; Neurodevelopmental Disorders; Portugal; Transition to Adult Care

RESUMO

Introdução: As perturbações do neurodesenvolvimento são caracterizadas pelo atraso ou alteração na aquisição de capacidades em vários domínios do desenvolvimento: motor, social, de linguagem e cognitivo. Deste modo, estas perturbações podem manifestar-se desde a infância até à vida adulta, exigindo a continuidade dos cuidados de saúde. Contudo, vários estudos mostram que existem limitações de acesso dos adultos aos cuidados de saúde nesta área clínica.

Métodos: Foi realizado um estudo observacional descritivo transversal através da aplicação de um questionário anónimo a médicos de Psiquiatria, a nível nacional, no período compreendido entre 6 de outubro e 6 de dezembro de 2020.

Resultados: Foram recolhidos dados de 83 médicos de Psiquiatria (43 internos de especialidade e 40 especialistas). A nível nacional, apenas 16,9% dos serviços de Psiquiatria tinham uma consulta diferenciada de neurodesenvolvimento. Os médicos respondentes reportaram ter observado poucos doentes com perturbações do neurodesenvolvimento: 72,3% observaram um ou nenhum por semana. Dos médicos que referiram ter consulta de neurodesenvolvimento no seu serviço, a maioria (64,3%) não dispunha de equipa multidisciplinar. A transição destes doentes da consulta de Pediatria do Neurodesenvolvimento/Pedopsiquiatria para a de Psiquiatria ocorria em 51,8% por transferência regular intra-hospitalar, contudo em apenas 15,7% ocorria através de protocolo específico ou com a realização de consulta de transição. Por fim, 88% dos médicos de Psiquiatria consideraram ser pertinente a existência de uma consulta de perturbações do neurodesenvolvimento no adulto e relataram não possuir formação especializada na área do neurodesenvolvimento.

Conclusão: Este estudo possibilitou enumerar alguns obstáculos para que os doentes com perturbações do neurodesenvolvimento usufruam de uma transição de cuidados de saúde para a vida adulta favorável: carência de conhecimento na área, necessidade de melhor comunicação entre serviços, falta de protocolos específicos, escassez de equipas multidisciplinares e assimetria na distribuição de cuidados de saúde diferenciados.

Palavras-chave: Perturbação do Espetro do Autismo; Perturbação de Hiperatividade e Défice de Atenção; Perturbações do Neurodesenvolvimento; Portugal; Serviços de Saúde Mental; Transição para Assistência do Adulto

INTRODUCTION

A new diagnostic class of neurodevelopmental disorders (NDDs) was introduced in 2013 by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5),[1] including a heterogeneous group of conditions characterised by a delay or impairment in the acquisition of skills in different developmental domains: motor, social, language and cognitive.[2] These disorders are related to abnormal brain maturation, preceding the first clinical manifestations, leading to deficits in personal, social, academic or professional functioning and, subsequently, impaired quality of life.[3,4] Out of the different pathologies that fall under the designation of NDDs, this paper focuses on autism spectrum disorder

1. Faculdade de Medicina. Universidade de Coimbra. Coimbra. Portugal.
2. Instituto de Psicologia Médica. Faculdade de Medicina. Universidade de Coimbra. Portugal.
3. Serviço de Psiquiatria. Centro Hospitalar e Universitário de Coimbra. Coimbra. Portugal.
✉ **Autor correspondente:** Joana Costa Alves. joanacostaalves@gmail.com
Recebido/*Received*: 22/01/2023 - **Aceite/*Accepted*:** 26/05/2023 - **Publicado *Online*/*Published Online*:** 22/08/2023 - **Publicado/*Published*:** 04/12/2023

(ASD) and attention-deficit/hyperactivity disorder (ADHD).[2]

ASD affects approximately 1% of the population in the United States and other countries,[3,5] characterised by challenges in communication and social interaction, restrictive and repetitive behaviours and interests, with a gradual onset during early childhood.[3,6,7] Treatment depends on the patient's age: while working on communication and social interaction is relevant at younger ages, the promotion of functional autonomy is crucial in adulthood.[8]

ADHD is the most common neurodevelopmental disorder in the younger population,[2] estimated to affect 5% of children and 2.5% of adults in most cultures.[3] It is defined by the presence of signs of inattention, impulsivity and/or hyperactivity that are harmful to neurodevelopment.[3,9,10] Clinical manifestations must have started before the age of 12 and within more than one context (for instance at school/work and at home), for a confirmed diagnosis to be established.[3] The most effective way of reducing these symptoms is through pharmacological and behavioural intervention, both in children and in adults.[11]

Therefore, NDDs can develop from childhood to adulthood, and a continuity of care is crucial, especially within the period of transition to adulthood. This is a challenging period of development and critical for any young person, at a time when they are beginning to take on the autonomy and responsibilities of adult life. For young adults with ASD, it becomes an even more vulnerable period due to challenges in communication, social interaction, and the intrinsic adversity they show when faced with new situations.[12] As for young people with ADHD, even though hyperactivity may decrease during adulthood, inattention usually remains a problem.[3] New tasks are particularly challenging at this stage of their development, due to the constraints in time management, academic performance and establishing lasting social relationships.[13]

On the other hand, there is a frequent comorbidity with other psychiatric disorders. In ASD, 70% of the patients present with a comorbid psychiatric disorder and 40% may present with two or more,[3] and it is common for ADHD, anxiety disorder or depression to coexist.[6] As for ADHD, it can be a risk factor for defiant behaviour and violence, emotional problems, self-harm, and substance abuse, leading to more than half of these patients presenting with some psychiatric comorbidity.[10]

NDDs are related to a significant social and economic impact. In the United States of America, the annual costs of ASD and ADHD are of around 175 and 143 billion dollars (163 and 133 billion euros, respectively).[10,14] UK costs are estimated at around 29 billion pounds for ASD and 670 billion pounds for ADHD (34 and 737 billion euros, respectively).[10,14] The economic impact of NDDs is around three times higher in adults than in children and adolescents.[10] The most relevant factors in total cost, in both countries, included healthcare, educational services for children and lost productivity in adulthood.[10,14]

Despite all these reasons that underline the need for continuous monitoring of NDDs in the transition between paediatric and adult age, different studies have shown a limited access to adult healthcare, particularly in the transition from neurodevelopmental paediatric psychiatry departments to adult mental healthcare.[6,10,13,15] The Portuguese reality doesn't seem to be any different. Recommendations on child and adolescent mental health were published in primary healthcare in 2013 by the Directorate-General for Health (*Direção Geral de Saúde* - DGS),[16] which, despite specifically mentioning ASD and ADHD, do not address the transition to adulthood. In 2019, the DGS filled this gap, with the standard guideline 'Diagnostic Approach and Intervention in Autism Spectrum Disorder in Paediatric and Adult Age'.[16] The development of protocols for the coordination between hospital specialty/subspecialty outpatient clinics in neurodevelopmental paediatric psychiatry and adult psychiatry, as well as multidisciplinary teams to offer support during the transition to adulthood and during follow-up in hospital specialty outpatient clinics for adults are included in this guideline.[17] These standards were based on existing guidelines in other geographical areas, including Scotland and England. However, several studies from these countries have shown that the presence of protocols does not ensure that the clinical practice reflects what is advocated.[13,15]

This study was aimed at assessing the reality of adult psychiatric care at a national level as regards NDDs. Therefore, the specific endpoints of the study include (i) nationwide assessment of the presence and distribution of differentiated outpatient clinics; (ii) whenever present, characterisation of these clinics (team, tasks of each element and referral); (iii) analysis of the major constraints described by patients presenting with NDDs; (iv) analysis of the training in the area of neurodevelopment and what are the relevant topics.

METHODS

This was a cross-sectional descriptive observational study, aimed at assessing the experiences and opinions of psychiatrists (registrars and consultants) at a national level, using an anonymous questionnaire [Appendix 1

(Appendix 1: https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/19652/15210)]. As this study was carried out as part of an integrated master's thesis at the Faculty of Medicine of the University of Coimbra, ethical requirements were assessed and ensured by the scientific advisors.

The questionnaire was made available online between October 6 and December 6, 2020. Invitations were sent via e-mail to the heads of each psychiatry department at all Portuguese public hospitals, calling on the medical staff to share it.

In addition, the collaboration of national private institutions specialised in the treatment of NDDs that also treat adult patients was requested, namely the *Centro de Apoio ao Desenvolvimento Infantil* (CADIn) and *Progresso Infantil* (PIN). The support of the Portuguese Association of Psychiatry Registrars (*Associação Portuguesa de Internos de Psiquiatria* - APIP) was ensured, aimed at the disclosure among registrars. Later, the collaboration of the Portuguese Society of Psychiatry and Mental Health (*Sociedade Portuguesa de Psiquiatria e Saúde Mental* - SPPSM) was obtained, to strengthen the participation of consultants, by sending the questionnaire by e-mail to all SPPSM members.

The questionnaire included a short explanation of the objectives and relevance of this project, an informed consent, and the final three digits of the respondent's ID card were requested, to avoid accidental duplication of responses. This was followed by a 22-item questionnaire designed for the study [Appendix 1 (Appendix 1: https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/19652/15210)]: the initial 10 items were designed to characterise the sample at a sociodemographic level; the following 12 items were developed to respond to the objectives of the study, allowing for the characterisation of the different psychiatric outpatient clinics nationwide and the presence of a specific NDD consultation.

A total of 87 responses were obtained, out of 1,208 psychiatrists (registrars and consultants) working in Portugal, according to statistical data published by the Portuguese Medical Association in 2019.[18] However, only 83 were considered for the purposes of the analysis, as four responses were excluded due to duplication. No questionnaires were obtained from physicians working full-time in the private sector, following contacts with the two private institutions mentioned above. Data regarding the autonomous region of Madeira were not made available.

The descriptive analysis of the qualitative variables was carried out by assessing the frequency of responses and percentages, while the analysis of the quantitative variables included mean, standard deviation, minimum, maximum, and median. A 95% confidence interval was also obtained for the proportion of respondents who considered relevant an adult NDD consultation, using two online calculators[19,20] that showed coincident results.

The authors declare that the procedures complied with the regulations established by the heads of the Clinical Research and Ethics Committee of the Faculty of Medicine of the University of Coimbra and in accordance with the 2013 update of the Declaration of Helsinki of the World Medical Association; they declare that they followed the protocols of their work centre regarding data publication, and they declare that they have no conflict of interest regarding this manuscript.

RESULTS

Demographic and professional data were obtained from a convenience sample of 83 psychiatrists (43 registrars and 40 consultants) nationwide (Table 1).

Most registrars were single (67.4%) and female (62.8%), with an average age of 30 (30 ± 3). Most had a master's degree (95.3%), had worked full-time in the public sector (65.1%) and had on average three years of practice as psychiatrists (3 ± 1).

Most consultants were female (62.5%) and married or in a civil partnership (67.5%), with an average age of 45 (45 ± 11). Half of these had a bachelor's degree and 45% a master's degree, had worked for an average of 17 years (17 ± 10) and had mostly worked both in the public and private sector (72.5%).

As regards professional characteristics, 97.5% of the registrars included in the study and 97.5% of the consultants performed care duties, while 10% of the consultants also had coordination tasks. Most had no specific training in neurodevelopment, and only 7% of the registrars and 17.5% of the consultants have described some pre-graduate training and only one has described post-graduate training (PhD) in neurodevelopment.

Responses originated predominantly from central hospitals (61.4%), which included 19.3% from university hospitals and 42.2% from non-university hospitals, and mostly from the Northern (36.1%) and Lisbon and the Tagus Valley (34.9%) regions.

Geriatric psychiatry consultation was the most frequent (59%) nationwide, followed by early intervention in psychosis (34.9%), addictions (27.7%), young adult/adolescent

Table 1 – Demography, social and professional characteristics

Variable	Registrar (n = 43)	Consultant (n = 40)	Total (n = 83)
1. Sexo:			
Female	27 (62.8%)	25 (62.5%)	52 (62.7%)
Male	16 (37.2%)	15 (37.5%)	31 (37.3%)
2. Age	30 ± 3 Minimum = 26 Maximum = 41 Median = 29	45 ± 11 Minimum = 31 Maximum = 66 Median = 41	-
3. Marital status:			
Married / civil partnership	14 (32.6%)	27 (67.5%)	41 (49.4%)
Single	29 (67.4%)	12 (30%)	41 (49.4%)
Widower	0	1 (2.5%)	1 (1.2%)
Divorced	0	0	0
4. Education:			
Graduation	1 (2.3%)	20 (50%)	21 (25.3%)
Master's degree	41 (95.3%)	18 (45%)	59 (71.1%)
PhD	1 (2.3%)	2 (5%)	3 (3.6%)
6. Number of years of medical practice as a psychiatrist	3 ± 1 Minimum = 1 Maximum = 6 Median = 3	17 ± 10 Minimum = 3 Maximum = 36 Median = 13.5	-
7. Work type			
Public sector	28 (65.1%)	11 (27.5%)	39 (47%)
Private sector	0	0	0
Both	15 (34.9%)	29 (72.5%)	44 (53%)
8. Workplace			
Central university hospital	11 (25.6%)	5 (12.5%)	16 (19.3%)
Central non-university hospital	16 (37.2%)	19 (47.5%)	35 (42.2%)
Non-central hospital	16 (37.2%)	16 (40%)	32 (38.6%)
9. Hospital location			
Northern region	11 (25.6%)	19 (47.5%)	30 (36.1%)
Central region	10 (23.3%)	3 (7.5%)	13 (15.7%)
Lisbon The Tagus Valley region	15 (34.9%)	14 (35%)	29 (34.9%)
Alentejo	4 (9.3%)	1 (2.5%)	5 (6%)
Algarve	2 (4.7%)	2 (5%)	4 (4.8%)
Azores	1 (2.3%)	1 (2.5%)	2 (2.4%)
Madeira	0	0	0
10. Main functions			
Academic	9 (20.9%)	10 (25%)	19 (22.9%)
Healthcare	43 (100%)	39 (97.5%)	82 (98.8%)
Research	10 (23.3%)	7 (17.5%)	17 (20.5%)
Other(s)	0	4 (10%)	4 (4.8%)
13. Specific training in neurodevelopment			
No	40 (93%)	33 (82.5%)	73 (88%)
Yes	3 (7%)	7 (17.5%)	10 (12%)

The qualitative variables are shown as response frequencies and percentages (%), while quantitative variables as mean ± standard deviation, minimum, maximum and median.

psychiatry (26.5%), eating disorders (21.7%) and suicide prevention (13.3%).

As regards the differentiated neurodevelopment consultation, this was only found within a small percentage of public hospitals (16.9%). Most physicians (72.3%) have described as looking after only one or no patients with neurodevelopmental pathologies (median of 1) and only 27.7% have described as looking after two or more patients a week, with a maximum of 10.

From the respondents who have described a neurodevelopmental consultation in their department, 57.1% worked in the Central region, 21.4% in the Northern and 21.4% in the Lisbon and the Tagus Valley region, allowing for the assessment of the national distribution of this consultation (Fig. 1).

There was some heterogeneity regarding the designation of the differentiated neurodevelopment consultation. While in the Central region this was coded as an adult NDD consultation, it was designed as 'neuropsychiatry' in the Lisbon and the Tagus Valley region and was only attended by patients presenting with ADHD.

Neurodevelopmental consultations were not multidisciplinary, involving only a psychiatrist. The presence of nursing and psychology was only described by 35.7% of the respondents, social services by 21.4% and occupational therapy or speech therapy were not described.

It is worth mentioning that the consultation was mostly attended by patients who were referred within the hospital (51.8%), in addition to 26.5% of the patients who were referred by primary healthcare. Only in 10.8% were the patients referred by a specific protocol between departments and 4.8% of the patients were referred for a transitional consultation, in the presence of a neurodevelopmental paediatrician/psychiatrist and a psychiatrist.

The presence of a specific adult NDD consultation was considered relevant by most respondents (registrars and consultants) [88%, with a 95% confidence interval (79%, 94%)].

The introduction of an internship in this area within the psychiatry medical internship was considered relevant by 62.8% of the specialty registrars, suggesting the presence of an optional internship or the inclusion into the child and adolescent psychiatry internship.

Three major constraints were described by the patients and found by most respondents, including (i) challenges in social interaction/social isolation (69.9%), occupational and work challenges (66.3%) and delay and difficult diagnosis (56.6%).

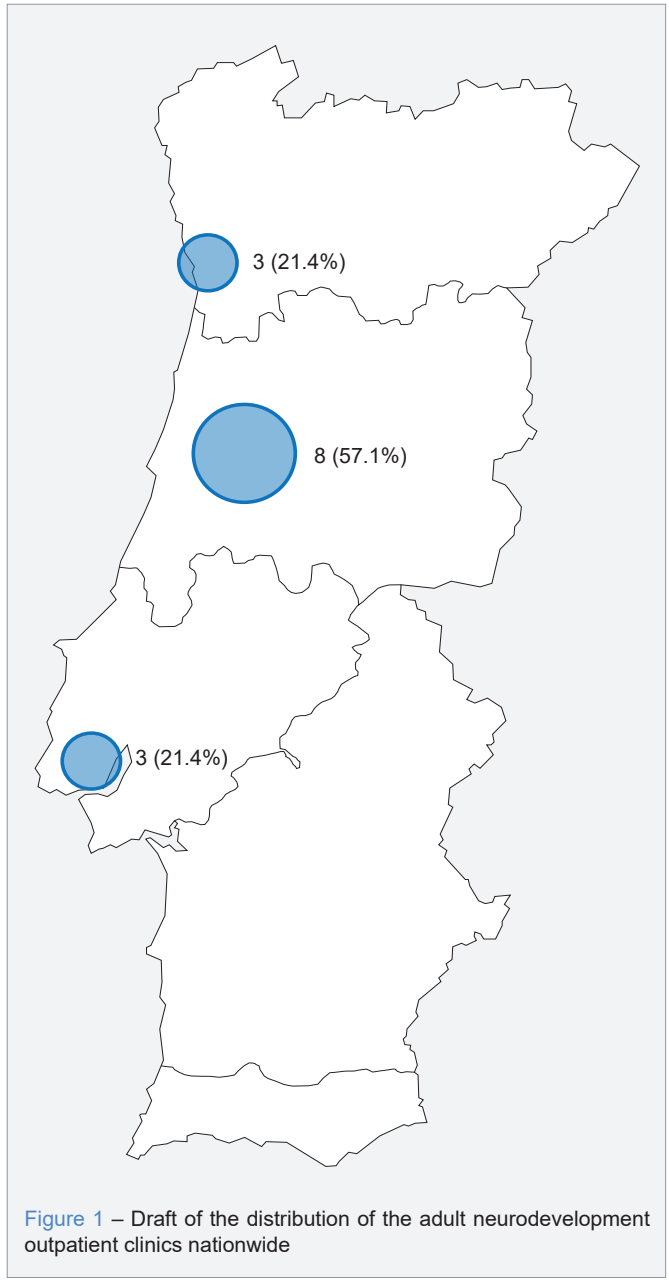

Figure 1 – Draft of the distribution of the adult neurodevelopment outpatient clinics nationwide

The major clinical tasks in the approach to patients, as described by respondents, included (i) carrying out clinical and diagnostic assessments (91.6%) and (ii) defining a psychopharmacological treatment for psychiatric comorbidities (90.4%). The following were also described by respondents: rehabilitation, referral to community responses for work/occupational integration and coordination with community support and stimulation structures. On the other hand, the following were considered essential by nurses:

psychoeducation groups for family members (85.5%), management of stress factors in the family/institutional environment (75.9%) and coordination with institutions (57.8%). Finally, respondents also described the benefits of the involvement of psychologists in holding social skills training groups (66.3%).

The respondents' opinion on which topics should be further developed by psychiatrists working in the NDD consultation was also asked and 89.2% of the respondents have considered that specialised training in NDD diagnosis was required, namely on the differential diagnosis with other psychiatric disorders (for instance, schizoaffective disorder *vs.* schizophrenia) as well as in genetic syndromes in NDD.

DISCUSSION

To the best of our knowledge, this is the first analysis of the Portuguese reality in adult psychiatric care regarding patients presenting with NDDs, as the organisation and accessibility of healthcare services in the transition phase to adulthood are crucial for the follow-up and well-being of these patients. The continuity of this follow-up also leads to a reduction in healthcare costs, as a favourable outcome can translate into increased productivity and independence for these patients in adulthood.[10,14,21]

The diagnosis of NDD in adult patients appears to be an undervalued and underestimated area, given that 81.9% of respondents have described the absence of this consultation in their departments, which may show the need to raise awareness of the importance of these pathologies. Given the small number of patients (on average, one patient per week), it is suggested that these pathologies may be underdiagnosed and, subsequently, there may be therapeutic requirements that are not being met, with patients requiring specialised follow-up. Even so, there are already different studies focused on the constraints described by patients presenting with NDD during the switch to adult mental healthcare services, although few focus on the organisation of psychiatric healthcare in this area, particularly in Portugal.

Caregivers and healthcare professionals claim that the lack of knowledge in this area promotes the therapeutic gap and hinders the transition of care.[9,22,23] In the present study, it was found that 88% of psychiatrists (registrars and consultants) had no training in neurodevelopment. The significant percentage of respondents (89.2%) describing the importance of deepen their knowledge in this subject was related to this reason.

As regards the medical internship, 62.8% of respondents suggested the development of an optional internship in neurodevelopment or the inclusion of the study of these pathologies in child psychiatry internship. However, the specificities of NDD in adulthood have been described in different studies,[8,11] and it seems insufficient that psychiatry training should be based solely on observing these pathologies in paediatrics. It was suggested, particularly by consultants, that the Portuguese Medical Association should create a specific competence dedicated to neurodevelopment.

Only 16.9% of respondents have considered the lack of support from healthcare services to be one of the major constraints experienced by patients with NDD. However, caregivers have described little support from healthcare services, especially in this stage of transition to adulthood in several studies published internationally.[24,25] The perspective of patients and their families about their experiences should therefore be considered to assess whether the Portuguese reality is in line with other countries.

The lack of communication between paediatric and adult healthcare services is another constraint to accessing and providing continuity of care specifically for these patients, which has also been mentioned in different studies.[24,26,27] In this study, we found that 51.8% of the patients were referred within the hospital. However, 26.5% of the patients were referred after paediatric follow-up by primary healthcare, which could mean more bureaucracy, wasted time/therapeutic effort and loss of clinical information. Different studies have shown that both the presence of defined protocols between the different departments,[15,22,23] and the possibility for patients to get to know their future care team before referral[6,21] would greatly improve the transition experience. However, this study found that only in a minority of cases does a consultation take place in the presence of the neurodevelopmental paediatrician/psychiatrist and psychiatrist (4.8%) or is there a specific protocol between departments (10.8%).

In summary, the results found in this study have shown the presence of constraints in accessing psychiatric care for patients with NDD in early adulthood in Portugal, namely the lack of knowledge in the area, the failure in communication between paediatric and adult healthcare services, the lack of protocols, the scarcity of this consultation and the asymmetrical distribution of this consultation nationwide.

Guidelines for clinical practice, such as those from the European Psychiatric Association[28] and The National Institute for Health and Care Excellence,[29,30] reinforce some of the topics mentioned above, namely the need to train physicians in NDD, a formal meeting involving paediatric and

adult mental healthcare services, the inclusion of patients and parents in decision-making processes, as well as the development of specific clinical guidelines.

Reputable international research centres, including the King's College London (UK), Stanford University in California (USA) and the Centre for Addiction and Mental Health (CAMH) in Toronto (Canada), strongly support the concept of providing specialised healthcare in an interprofessional approach, stressing the importance of each element of the multidisciplinary team in a neurodevelopmental consultation. In Portugal, the DGS standard on ASD in adulthood,[17] drawn up based on those guidelines, also highlights the importance of a multidisciplinary team, as well as the creation of protocols for coordination between the specific neurodevelopmental paediatric and adult outpatient clinics. This multidisciplinary team should include psychiatry, neurology, psychology, nursing, social work, speech therapy and occupational therapy, among others.

However, according to the data collected in this study, the clinical team consists only of a psychiatrist in most adult NDD outpatient clinics. Only 35.7% include a nurse or psychologist and there is no occupational or speech therapy care in this consultation, showing the lack of these technicians in the adult psychiatry department.

Given the specific characteristics of neurodevelopmental disorders, the transition to adult healthcare would benefit from professionals trained in the area, particularly in nursing, psychology, and occupational therapy. In ASD, patients have described challenges in social relationships and emotional regulation, which could be alleviated with the intervention of a psychologist, particularly in a group treatment approach.[31] As regards ADHD, on the other hand, nursing teams should intervene over a longer follow-up period to encourage healthier lifestyle habits.[32] As these patients show great constraints in interpersonal relationships, leading to feelings of failure and low self-esteem, a qualified psychologist could help understanding and improving the experience in these areas.[33] In both ASD and ADHD, given the common presence of impaired sensory function, occupational therapy can play a crucial role in identifying and treating occupational performance problems resulting from sensory modulation, sensory integration, motor and psychosocial deficits.[34] However, psychoeducation groups for family members by nursing and social skills training groups with patients by psychology were considered by most respondents as the most relevant to be carried out by these professionals.

Despite the DGS's attempt to approach some of these constraints by drafting the standard in 2019, there is still a long way to go to improve access and psychiatric treatment for adults with NDD. In addition, international studies, particularly in Ireland and Italy, have reached the conclusion that these guidelines are not properly implemented and subsequently do not achieve the expected results.[13,15]

This study has some limitations, particularly as regards the representativeness of the sample. In addition to the number of respondents being less than 10% of the psychiatrists registered with the Portuguese Medical Association in 2019, the inclusion of physicians working full-time in the private sector and in the autonomous region of Madeira was not possible. In addition to these limitations, most respondents holding adult NDD consultations are working in the Central region, which could be due to sampling bias.

In the future, a more in-depth study with inferential statistics would be pertinent, assessing the opinion of the remaining medical community, including neurologists, neuropaediatricians, child psychiatrists, as well as the experience of patients and their caregivers regarding the medical care to be provided during the transition to adulthood. A unanimous perspective of the participants in this study seem to exist, regardless of the training in neurodevelopment, professional category, geographical area or experience in the field.

CONCLUSION

This study has shown that, throughout October 6 and December 6, 2020, an adult NDD outpatient clinic existed at only a minority (16.9%) of psychiatric departments nationwide, mainly located at the Central region, and in the Northern and Lisbon and the Tagus Valley regions.

These outpatient clinics only included a psychiatrist, whose main tasks, according to the respondents, included the clinical and diagnostic assessment and the prescription of psychopharmacological treatment for psychiatric comorbidities. Intra-hospital referral of patients to adult psychiatry was mostly found.

Finally, it was found that respondents (consultants and registrars) had no specific training in neurodevelopment, although the inclusion of this training into the psychiatry internship was considered as very relevant.

Some constraints to these patients into the transition to adulthood were found when assessing the characteristics of the national reality in adult psychiatric care regarding NDD. Taking the perspective of the patients into account, as well as their caregivers, community associations, in addition to the remaining medical community (including

neurologists, neuropaediatricians and child psychiatrists) and other healthcare professionals (speech therapists, psychologists and occupational therapists) seems therefore relevant.

ACKNOWLEDGMENTS

To Miguel Patrício for his support in the analysis and statistical revision.

To all the physicians for their voluntary response to the survey, as well as all the institutions that have collaborated with this project, namely CADIn, PIN, APIP and SPPSM.

AUTHOR CONTRIBUTION

JCA: Data collection, analysis, and interpretation, writing of the manuscript.

SM: Study design, conception, and methodology; writing of the manuscript.

AFM: Critical revision and final approval of the manuscript.

HUMAN AND ANIMAL PROTECTION

The authors declare that this project complied with the regulations that were established by the Ethics and Clinical Research Committee, according to the 2013 update of the Helsinki Declaration of the World Medical Association.

CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest in writing this manuscript.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

FINANCIAL SUPPORT

The authors declare that there was no financial support in writing this manuscript.

REFERENCES

1. Substance Abuse and Mental Health Services Administration. Impact of the DSM-IV to DSM-5 changes on the national survey on drug use and health. Rockville: Substance Abuse and Mental Health Services Administration; 2016.
2. Jeste SS. Neurodevelopmental behavioral and cognitive disorders. Continuum. 2015;21:690-714.
3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Washington, DC: American Psychiatric Publishing; 2013.
4. Thapar A, Cooper M, Rutter M. Neurodevelopmental disorders. Lancet Psychiatry. 2017;4:339-46.
5. Oliveira GG. Epidemiologia do autismo em Portugal: um estudo de prevalência da perturbação do espectro do autismo e de caracterização de uma amostra populacional de idade escolar. 2005. [cited 2023 Apr 18]. Available from: http://hdl.handle.net/10316/848.
6. King C, Merrick H, Le Couteur A. How should we support young people with ASD and mental health problems as they navigate the transition to adult life including access to adult healthcare services. Epidemiol Psychiatr Sci. 2020;29:e90.
7. Davignon MN, Qian Y, Massolo M, Croen LA. Psychiatric and medical conditions in transition-aged individuals with ASD. Pediatrics. 2018;141:S335-45.
8. Lord C, Brugha TS, Charman T, Cusack J, Dumas G, Frazier T, et al. Autism spectrum disorder. Nat Rev Dis Primers. 2020;6:1-23.
9. Price A, Mitchell S, Janssens A, Eke H, Ford T, Newlove-Delgado T. In transition with attention deficit hyperactivity disorder (ADHD): children's services clinicians' perspectives on the role of information in healthcare transitions for young people with ADHD. BMC Psychiatry. 2022;22:251.
10. Sayal K, Prasad V, Daley D, Ford T, Coghill D. ADHD in children and young people: prevalence, care pathways, and service provision. Lancet Psychiatry. 2018;5:175-86.
11. Faraone SV, Asherson P, Banaschewski T, Biederman J, Buitelaar JK, Ramos-Quiroga JA, et al. Attention-deficit/hyperactivity disorder. Nat Rev Dis Primers. 2015;1:15020.
12. Kuo AA, Anderson KA, Crapnell T, Lau L, Shattuck PT. Introduction to transitions in the life course of autism and other developmental disabilities. Pediatrics. 2018;141:S267-71.
13. Tatlow-Golden M, Gavin B, McNamara N, Singh S, Ford T, Paul M, et al. Transitioning from child and adolescent mental health services with attention-deficit hyperactivity disorder in Ireland: case note review. Early Interv Psychiatry. 2018;12:505-12.
14. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatrics. 2014;168:721-8.
15. Reale L, Costantino MA, Sequi M, Bonati M. Transition to adult mental health services for young people with ADHD. J Atten Disor. 2018;22:601-8.
16. Direção-Geral da Saúde. Programa nacional de saúde infantil e juvenil, atualizado em 31/05/2013 e publicado na Norma da DGS n.º 010/2013. Lisboa: DGS; 2013.
17. Direção-Geral da Saúde. Abordagem diagnóstica e intervenção na perturbação do espetro do autismo em idade pediátrica e no adulto. Publicado na norma da DGS n.º 002/2019 de 23/04/2019. Lisboa: DGS; 2019.
18. Ordem dos Médicos. Estatísticas de médicos inscritos na Ordem dos Médicos – estatísticas por especialidades; 2019. [cited 2019 Dec 29]. Available from: https://ordemdosmedicos.pt/wp-content/uploads/2020/01/ESTATISTICAS_ESPECIALIDADES_2019.pdf.
19. Kohn MA, Senyak J. Sample size calculators. UCSF CTSI. 2020. [cited 2021 Feb 02]. Available from: https://www.sample-size.net/.
20. Statistics Kingdom. Mann Whitney U test calculator. 2017. [cited 2021 Feb 02]. Available from: http://www.statskingdom.com/.
21. Zeng S, Strain A, Sung C. Health care transition services and adaptive and social-emotional functioning of youth with autism spectrum disorder. J Autism Dev Disord. 2021;51:589-99.
22. Nathenson RA, Zablotsky B. The transition to the adult health care system among youths with autism spectrum disorder. Psychiatr Serv. 2017;68:735-8.
23. Young S, Adamou M, Asherson P, Coghill D, Colley B, Gudjonsson G, et al. Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network. BMC Psychiatry. 2016;16:301.
24. Reale L, Frassica S, Gollner A, Bonati M. Transition to adult mental health services for young people with attention deficit hyperactivity

disorder in Italy: parents' and clinicians' experiences. Postgrad Med. 2015;127:671-6.
25. Cheak-Zamora NC, Teti M. "You think it's hard now… It gets much harder for our children": youth with autism and their caregiver's perspectives of health care transition services. Autism. 2015;19:992-1001.
26. Kuhlthau KA, Warfield ME, Hurson J, Delahaye J, Crossman MK. Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: current strategies and promising new directions. Autism. 2015;19:262-71.
27. Malik-Soni N, Shaker A, Luck H, Mullin AE, Wiley RE, Lewis ME, et al. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatr Res. 2022;91:1028-35.
28. Kooij JJ, Bijlenga D, Salerno L, Jaeschke R, Bitter I, Balázs J, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. Eur Psychiatry. 2019;56:14-34.
29. National Institute for Health and Care Excellence (NICE). Attention deficit hyperactivity disorder: diagnosis and management (NG87). London: NICE; 2018.
30. National Institute for Health and Care Excellence (NICE). Autism spectrum disorder in adults: diagnosis and management. London: NICE; 2012.
31. Hartmann K, Urbano MR, Raffaele CT, Kreiser NL, Williams TV, Qualls LR, et al. Outcomes of an emotion regulation intervention group in young adults with autism spectrum disorder. Bull Menninger Clin. 2019;83:259-77.
32. Björk A, Rönngren Y, Wall E, Vinberg S, Hellzen O, Olofsson N. A nurse-led lifestyle intervention for adult persons with attention-deficit/hyperactivity disorder (ADHD) in Sweden. Nord J Psychiatry. 2020;74:602-12.
33. Gentile JP, Atiq R. Psychotherapy for the patient with adult ADHD. Psychiatry. 2006;3:31.
34. American Occupational Therapy Association. Occupational therapy using a sensory integration-based approach with adult populations. Fact Sheet. North Bethesda; AOTA; 2011.